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information &
inspiration
to individuals with
disabilities and
their families
as they direct their
own supports and
services



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Real Life Choices: A Family Perspective

by Steve Smith

The Division of Developmental Disabilities has taken to the road to conduct family and consumer driven forums throughout the State. Many of the families involved with Real Life Choices are eager to share their stories with others just beginning their journey into the DDD initiative.

These families are the “pioneers of Real Life Choices” states Kathy Palsho, Director of Systems Change and Transformation for DDD. Several of the families have inspiring success stories of their experiences with the Real Life Choices process and one story of note is that of a young man named Daniel Miller.

Daniel is a consumer with the Division who is an energized participant in Real Life Choices.

Living in Ocean City, Cape May

County, Daniel has been a part of the city Public Works Department honing his work skills with responsibilities like car washing, facilities management and assistance with the sanitation crew. And because of his work with the city, Daniel is also a tremendous advocate for the area who instinctively promotes the city and its attractions. If you need to know of a great fishing location, he’s your man.

Daniel’s parents, Mr. & Mrs. Miller, have seen the benefits of Real Life Choices in that their son is more confident and much more independent because of the opportunities he has had through the initiative. Mrs. Miller recounted how after the budget and Essential Lifestyle Plan were completed they needed to hire someone to work with Daniel. Based on a recommendation from a DDD staff member, they interviewed and soon after hired a young college student named Conner to work with Daniel for about 16-20 hours per week.

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continues on page 4



News From Washington D.C.

Technology Bill Waits for the President's Signature

The U.S. House of Representatives overwhelmingly passed legislation authored by 21st Century Competitiveness Subcommittee Chairman Howard P. "Buck" McKeon (R-CA) to expand access to technology for individuals with disabilities. The bill, the Assistive Technology Act of 2004 (H.R. 4278), is now headed to President Bush for his signature.

The Assistive Technology Act primarily funds state programs that provide assistive technology (AT) devices and services to individuals with disabilities. The bill provides a minimum state grant of \$410,000. The "sunset provision" is waived, meaning that AT will now be regularly reauthorized by Congress.

"This bill shifts the focus of the program to provide greater benefit to individuals with disabilities. Our goal is to help states get more assistive technology directly into the hands of individuals with disabilities," said McKeon. "I know this will help states continue to make progress in their efforts to expand access to assistive technology, and that increasing numbers of individuals with disabilities will be able to participate in society more fully everyday."

The House and Senate worked in a bi-cameral, bi-partisan fashion to move assistive technology reauthorization along a fast track, without the need for going to a conference committee before the bill is signed into law. The bipartisan bill, approved earlier by the U.S. Senate, will strengthen assistive technology programs by refocusing resources to provide more direct aid to individuals with disabilities. By requiring states to spend the majority of their assistive technology grants on activities that directly benefit individuals with disabilities, the Assistive Technology Act of 2004 will help guarantee individuals will have greater access to assistive technology. The bill encourages states to invest in the programs that have been shown the most effective in providing assistive technology devices.

For a summary of the Assistive Technology Act of 2004: www.edworkforce.house.gov/issues/108th/education/at/bill-summary.htm

\$31 Million in Grants to Help Individuals with Disabilities

New Jersey Awarded Funds for Quality Assurance

The U.S. Department of Health and Human Services announced \$31 million in grants to states to help people with disabilities or long-term illnesses live in their homes and participate fully in community life. The grants are a part of the "New Freedom Initiative." Under this initiative, federal agencies work with states and community organizations to remove barriers to community living for people with disabilities and those with long term illnesses.

New Jersey is among nine states to receive funding to support quality assurance and quality improvement in home-and community-based services. The programs identify key quality indicators through input from consumers, family and other stakeholders.

Nine areas were funded:

- **Quality Assurance** (\$4.3million to nine states)
- **Integrating housing needs with other support systems** (\$6.7 million to eight states)
- **Screening, assessment and transition from children's services to adult services** (\$1 million to Nebraska and Washington, D.C.)
- **Reform of long-term support systems** (\$7.6 million to two states)
- **Mental health systems reform** (\$3.3 million to eleven states)
- **Rebalancing initiative** to reduce institutionalization (\$2 million to seven states)
- **Living with Independence, Freedom, and Equality** (\$200,000 to two states)
- **Family-to-family health care information and education centers** (\$1.5 million to private, not-for-profit entities in 10 states to develop and implement an information and referral network for parents of children with special health needs.)
- **National State-to-State Technical Assistance Program for Community Living** (\$4 million to the Independent Living Research Utilization program in Texas to offer technical assistance to grantees.)

Additional information is available at: www.cms.hhs.gov/newfreedom/accomplish2.pdf and www.cms.hhs.gov/newfreedom/default.asp

Advocacy Works!!

Cost of Living Adjustments Extended to Those in Self - Directed Services

"...thank you to Governor James McGreevey and Acting Director of DDD, Carol Grant for their support in this area. I hope this positive outcome encourages all of us to never forget that political advocacy is the catalyst for change and never to be afraid to express our concerns to our elected representatives."

- Bill England

This summer, Self-Determination Support Broker and advocate Bill England sent a letter to former Governor Jim McGreevey concerning the funding discrepancy between the Cost of Living Increases of staff in Institutions, the Agency Support system and those people receiving support in Self Directed platforms, such as, Self-Determination. The Governor's budget included a 4% adjustment for agency staff, but did not appear to address staff in self-directed services.

His advocacy had a positive outcome. The Governor's office, through Carol Grant, Director of DDD, responded to England's inquiry and informed him that **the COLA in the FY '05 budget does include a COLA increase for self-directed services.**

This fall, the Division of Developmental Disabilities (DDD) will contact those individuals and families who have self-directed plans for over one year old who are eligible for a COLA increase.

According to Grant, DDD agrees that it is essential that a COLA increase should be provided for the cost of services and for employees who provide self-directed supports and assured the self-directed supports will be included in any future requests for COLAs.

Advocacy at the Federal Level

Direct Support Fairness and Security

U.S. House of Representatives members Lee Terry (R-NE) and Lois Capps (D-CA) have introduced a bill to improve the salaries and benefits of direct support professionals.

The Direct Support Professional Fairness and Security Act would increase Medicaid reimbursement rates for staff salaries in certain targeted programs, including community based support services. The American Network of Community Options and Resources (ANCOR), United Cerebral Palsy, and The Arc of the United States will announce their support of Representatives Terry and Capps for their leadership in addressing the crisis in availability of direct support workers.

The legislation was unveiled at the ANCOR conference in Washington, D.C. Look for more information.

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Daniel

Continues from cover

Daniel took to Conner immediately as he exposed Daniel to a wonderful new world which his parents could not, college life. Daniel has been able to go surfing, play golf, and meet new friends. Conner has even inspired Daniel to find his perfect match in a girlfriend some day soon. Daniel explained that he really has fun with Conner, but that it's not all play. They have had the opportunity to greater develop Daniel's household skills, like washing clothes, cleaning and even cooking.

On one special night, Mr. & Mrs. Miller were ordered away from the house for a few hours so that Daniel and Conner could surprise them with a wonder home cooked meal. This was a pleasant treat for Daniel's parents and reinforced the strengths of Real Life Choices, placing opportunities in families' lives to allow for more choices. Mr. & Mrs. Miller have enjoyed nights alone or out on the town together for the first time in years. They see a more calm, sure and self-reliant Daniel and Mrs. Miller feels they "owe it to Real Life Choices".

As the "pioneers" of Real Life Choices, all of the families involved are learning this new system and enjoying a level of creativity not seen before in the Division. The emphasis is on generating more choices for individuals and their families and as Kathy Palsho has stated to the individuals with disabilities and their families the Division is "funding you so that you have the flexibility to meet your unique needs, aspirations and life style."

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